30 FOR 30 CAMPAIGN

BRIEFING PAPER

Making HIV Prevention Work for Women

Advocacy • Equity • Action

Introduction

With the implementation of the National HIV/AIDS Strategy (NHAS), the Affordable Care Act (ACA), and the continuation of the Ryan White CARE Act, we find ourselves in a fast-paced and dramatically changing health care delivery environment for all people. For people living with or affected by HIV these changes will provide great opportunities and challenges.

The Affordable Care Act has already provided opportunities for strides in women's health including the adoption of the Institute of Medicine (IOM) guidelines on women's preventive health such as free HIV testing, intimate partner violence prevention and counseling, and sexually transmitted infection (STI) counseling. These types of critical services for women must also be explicitly integrated into HIV prevention and care.

- Women enter later into HIV care;
- Women have a lower likelihood of receiving antiretroviral therapy;
- Women have twice as many HIV-related illnesses; and
- Women have higher mortality rates.[3]

Ample evidence shows these disparities are related to a confluence of race, gender, socioeconomic, and geographic factors that uniquely affect the health outcomes of women.

- Women most at risk or living with HIV are **disproportionately low income** – 64% of HIV-positive women in care have annual incomes below $10,000, compared to 41% of men;
- Women most at risk or living with HIV are more likely to have **caretaking responsibilities** – 76% of women in HIV care have children under 18 in their homes, which can make accessing care more complicated;
- **Transgender women** living with HIV are likely to **face unique challenges** in adhering to HIV care and treatment regiments, due to economic marginalization, stigma and past negative experiences with providers as well as

The 30 for 30 Campaign is dedicated to ensuring that the unique needs of women living with and affected by HIV, including transgender women, are addressed in the national HIV response. We are especially committed to illuminating and eliminating the gaps in prevention and care services for Black and Latina women who currently make up over 80% of the epidemic among women but only 12% and 14% of the US female population respectively.[1]

The Campaign is concerned with the current state of HIV prevention and care for women as studies continue to show that women, especially women of color, have consistently poorer health outcomes despite there being no significant clinical difference in treating men or women living with HIV.[2]

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concerns about adverse interactions between antiretroviral medication and hormone therapy.[4]

- Women of color have among the **highest HIV and STI prevalence** but do not have the highest levels of risk behaviors;[5] and
- Women most at risk or living with HIV are more likely to have experienced **sexual or intimate partner violence** at some point in their lives increasing their risk for HIV or fear of disclosure once diagnosed. Nearly one in four women report they have been subjected to "severe physical violence" by an intimate partner compared to one in seven men[6]. Transgender women and girls face pervasive violence from their families, partners, strangers, institutions, colleagues, teachers and peers.

These factors make HIV prevention, and effective linkages to, and retention in HIV care for women particularly challenging. For this reason, given that treatment can be prevention, our national HIV response must account for the unique prevention and care needs of women, including transgender women, in every aspect of relevant policy and programming.

HIV Prevention that Works for Women

A broad and credible evidence base exists showing what works to prevent HIV among women and girls in the U.S. But this evidence and the corresponding tools are far from being optimally utilized, and our knowledge base on what works for transgender women and girls must be augmented. Unflinching analysis of the specific needs and rights of women living with and affected by HIV leads us to solutions that, if implemented, can help turn the tide of the HIV epidemic. Greater political will and commitment to addressing the root causes and structural drivers of HIV is needed in order to make successful HIV prevention and care for women and their communities a promise kept, not just a promise made.

Exertion of this political will and commitment is needed now because of the rapid and fundamental changes being shaped by implementation of the National HIV/AIDS Strategy (NHAS) and the Affordable Care Act (ACA). While all HIV/AIDS programming and funding is moving into place in accordance with the NHAS blueprint, the ACA is simultaneously changing our health care delivery landscape. If the recommendations presented here are not rapidly and explicitly incorporated into both processes, they will remain absent from the new health care environment being created around us and, thus, will likely remain unaddressed indefinitely.

This paper addresses the most urgent prevention issues confronted by women and girls currently at highest risk of HIV and those living with HIV in the U.S. It is by no means, a comprehensive view of the needs and issues women face across their lifespans, but rather a selective look at what needs to be and can be done now in the context of our changing environment to make an immediate difference.

WHAT WE KNOW

In order to address women's most urgent HIV prevention needs we must move beyond interventions solely focused on personal behaviours to those that tackle the epidemic's structural drivers such as poverty and racism – strategies that the CDC notes address and modify the societal, rather than individual, determinants of disease transmission and risk.[7] Social scientists Gupta et al note that, "one of the most important justifications for an increased use of structural approaches is to avoid past failures in oversimplified, individually oriented behavioural interventions across diverse populations."[8]

In light of what we know the most urgent priorities for advancing HIV prevention for women in the U.S. are:

1. Integration of three currently siloed areas of health care delivery: a) HIV prevention, treatment and care; b) sexual and reproductive health (SRH) services; and c) intimate partner violence (IPV) prevention, treatment and services.

2. Expanded research into, and targeted education on, current and future HIV prevention tools including "treatment as prevention," Pre-exposure Prophylaxis (PrEP), female condoms, microbicides and the potential impact of hormonal contraception use on HIV risk.

Why Integrated Health Care Delivery and Woman Controlled Prevention Matter

A recent Institute of Medicine report whose guidelines were adopted by The Department of Health and Human Services (HHS) notes that the Patient Protection and Affordable Care Act (ACA) signals a profound shift in the U.S. away from a reactive system of medical care and toward a system more focused

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on primary care and prevention.[9] Written to identify critical service gaps not addressed in ACA guidelines, the report recommends, among other things, the addition of "a fuller range of contraceptive education, counselling, methods and services" and that "all women and adolescent girls be screened and counselled for interpersonal and domestic violence in a culturally sensitive manner", since "[s]creening for risk of abuse is central to women's safety, as well as to addressing current health concerns and preventing future health problems."[10]

Federal data show that nearly five million women accessed federally funded family planning services in 2010 but fewer than two in ten of them accessed HIV testing during their clinic visits.[11] This is a missed opportunity to reach women who may be at risk for HIV or women living with HIV who may require family planning or reproductive health services tailored to their specific health needs. Evidence compiled over the last decade decisively shows that women are most vulnerable to HIV when their sexual and reproductive health and rights are not adequately addressed. *What Works for Women*, a best-practices review of 455 studies of HIV-related programming around the world, states that "integrating HIV testing and services with family planning, maternal health care or within primary care facilities can increase uptake of HIV testing and other reproductive health services."[12] A Joint United Nations Programme on HIV/AIDS (UNAIDS) literature review similarly concluded that linking sexual and reproductive health services with HIV services uniformly results – even across highly diverse settings – in "improvements in health outcomes including access to and uptake of services, condom use, knowledge of HIV and STIs, and overall quality of health services."[13]

The Health Resources and Services Administration (HRSA) notes that fewer than 10% of all providers of HIV services routinely screen for intimate partner violence (IPV), despite evidence that its incidence is "highly disproportionate among populations at risk for HIV."[14] One study showed that only 16% of physicians had an office protocol in place for serving a woman who reports that she is experiencing IPV.[15] This failure of appropriate action occurs in a country in which the Attorney General has described the rates of intimate partner violence against American women and girls as "staggering."[16]

The integration of HIV-related services with services to prevent, treat and respond to IPV is urgently needed. The link between IPV and HIV risk is clearly established in international research. [17,18,19,20] A strong association between IPV and HIV risk was demonstrated in a 2009 U.S. study of over 34,000 women participants in the National Epidemiologic Survey on Alcohol and Related Conditions.[21] This study's authors reported that "in the United States, approximately 12% of HIV/AIDS infections among women in romantic relationships are due to IPV," adding that, "[d]ue to the lack of assessment of lifetime exposure to IPV, this attributable fraction is probably an underestimate."[22] Another U.S. study showed that teenaged girls in abusive relationships were almost three times more likely to report infection with HIV or another STI than girls of similar age whose partners were not abusive.[23]

Women are most vulnerable to HIV when their sexual and reproductive health and rights are not adequately addressed.

HIV risk for women, including transgender women, increases in the context of IPV for many reasons; directly through rape and other physical/sexual abuse, and indirectly when a woman is unable to negotiate condom use, engages in high-risk behaviors associated with IPV-generated post-traumatic stress disorder, or resorts to transactional sex for survival after her abuse leads to abandonment or homelessness.[24,25]

The confluence of social and structural factors such as the sexual and reproductive rights and desires of women, as well as the prevalence of intimate partner violence complicate HIV prevention for women and underscores the urgent need for varied forms of prevention tools that can be used without the active participation of, or consent of her partner such as female condoms, effective microbicides, or new biomedical tools.

WHAT NEEDS TO BE DONE MOST URGENTLY

Integration of HIV Prevention, Care and Treatment; Sexual and Reproductive Health Care; and Intimate Partner Violence Services

These three examples provide a glimpse of what effective integration might look like.

1. Voluntary and routine HIV counselling and testing can be offered to all clients receiving care in family planning and sexual/reproductive health care settings and by providers of IPV services.

2 STI screening, family planning and sexual health care information, and referrals for such care (if it is not available on-site) can be offered in all HIV/AIDS service provider settings.

3. Culturally-competent screening for intimate partner violence (IPV) and referrals for IPV prevention, treatment and support can be provided in all settings in which HIV-related services and sexual/reproductive health care are provided.

Achieving effective integration will require expanded investment in training providers in these three fields to not only be medically competent but also culturally competent to provide the highest quality of HIV prevention and care for women in all of their diversity. Concerted efforts to identify and prepare venues in existing and forthcoming health care services where such integration can be supported is necessary.

In a 2011 letter to 30 for 30, Deputy Assistant Secretary of Health Ron Valdisseri wrote that, "we will work with federal partners to identify opportunities for supporting efforts that better integrate HIV care with programs that serve the reproductive and sexual health needs of women." We value that assurance

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but we believe that meaningful integration of HIV prevention, care and treatment with sexual and reproductive heath care cannot be achieved without a substantially increased and more active commitment to integration within the National HIV/AIDS Strategy and Affordable Care Act Implementation processes than has occurred to date.

The NHAS gives significant attention to the importance of integrating mental health and substance abuse services into HIV prevention services, for example, yet the need to integrate SRH services into HIV screening and prevention is mentioned only once in the NHAS Implementation Plan – and then as a strategy for increasing the number and diversity of clinicians available to care for people with HIV.[26] While important, this sole mention ignores the proven ability of such targeted integration to improve both HIV and SRH care, especially for women of color, those living in poverty, and others affected by HIV. Similarly, IPV is mentioned in the NHAS, but the Implementation Plan contains no mention of IPV prevention services or incidence monitoring.

United States domestic HIV policy for women should incorporate some of the basic principles and requirements placed on recipients of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and Global Health Initiative (GHI) funding globally: an integrated approach to HIV prevention and care that provides comprehensive, client-centered, equitable, rights-

based care. In response to the recognition that "[v]oluntary family planning should be part of comprehensive quality care for persons living with HIV," [27] PEPFAR guidance suggests strong referral systems and where possible integrated SRH and HIV prevention and care programs. PEPFAR's implementation guidance, which recognizes the association between IPV and HIV risk emphasizes that HIV service integration efforts should include the addition of services to prevent and treat gender-based violence (the term used internationally, and in the PEPFAR guidance, for IPV). It describes such violence as, "a major contributing factor to HIV infection" and directs program managers to incorporate IPV services into their HIV prevention, care, and treatment programs in response to "consensus-based recommendations from public health experts, women's groups, reference agencies such as the WORLD Helath Organization (WHO) and the Centers for Disease Control and Prevention (CDC), academic researchers, development partners, and others."[28]

We contend that it is time for the U.S. government to follow domestically the same directives in this area that it has issued for use of U.S. tax dollars internationally. Data shows that IPV is increasing women's and girls' HIV risk, including transgender women and girls, here in the U.S. and an integrated response to that reality is required here at home.

The NHAS is regularly described as a living document. Therefore, the addition of goals and objectives regarding the integration of HIV, SRH and IPV service integration should be achievable, as should the assignment of responsibility for progress in these areas to specific federal offices. Without such markers, mechanisms for assessing progress and assuring accountability in these areas will not exist. Consequently, federal commitments to this critical integration remain hollow.

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Expanded and Accelerated Access to Female-Initiated HIV Prevention Tools

As yet there are no women-controlled prevention tools available. Male condoms aren't enough and female condoms cannot be used without a partner's knowledge and consent. Women urgently need expanded investment in and research into current and future HIV prevention tools including female condoms, Treatment as Prevention (TasP), Pre-exposure Prophylaxis (PrEP), microbicides and a better understanding of the impact of hormonal contraception use on HIV risk. The below examples are offered to provide some concrete ideas of how effective movement toward improved HIV prevention for women might be structured:

1. In collaboration with civil society advocates, the CDC should a) require, train and fund providers of male condom education and supplies for HIV prevention to also provide female condom education and promotion and to supply female condoms in quantities commensurate to the expressed need in their area; and b) design and launch a female condom skills building training and education initiative targeted to health care providers to overcome negative perceptions of its acceptability and to urge them to promote it to their patients in a positive, supportive way to actively encourage greater uptake.

2. One or more demonstration project(s) on the acceptability and impacts of PrEP among women at highest risk of HIV in the U.S., including transgender women, can be designed in collaboration with civil society groups and providers with the greatest experience working with these populations.

3. One or more demonstration project(s) should be implemented in areas with TLC+ initiatives and accelerated comprehensive HIV/AIDS planning and cross-agency response projects such as the HHS 12 Cities Project and CDC ECHPP. Demonstration project(s) can assess the barriers to reaching, linking, and retaining women in HIV care, and the impact that earlier uptake of HIV treatment is having on participating women and girls, including transgender women and girls, primarily in terms of their own health and secondarily in terms of their likelihood of transmitting HIV to others.

The U.S. has been the largest contributor to microbicides research globally and we applaud the sustained federal support for the development of microbicides and other HIV prevention tools to meet the needs of women and girls, as articulated in the NHAS. The need for HIV prevention tools that a woman can use without the active participation or consent of her partner remains urgent. Although new biomedical tools such as vaccines and microbicides, alone cannot gaurantee HIV prevention for women, they will provide essential options for those who are unable to insist on male condom use on a regular basis.

Female condoms, the only FDA-approved, female receptive partner-initiated dual protection prevention tool available, are nowhere mentioned in the NHAS. Research confirms that the two greatest barriers to widespread use of female condoms in the U.S. are lack of familiarity with female condoms, together with the relatively high purchase cost in comparison to male condoms. Not addressing these barriers vigorously constitutes a wasted HIV prevention opportunity.

One study among inner-city African-American women showed that participants with multiple sexual partners were five times more likely to use female condoms than monogamous women, once the product was effectively introduced and provided.[29] A California study showed that women who received female condom skills training not only used them more frequently than those who received a general women's health promotion intervention of comparable length but also reported a significantly higher percentage of protected sex acts (using male or female condoms) six months after the intervention than did the control group[30].

Given this research, and corroborating data from other studies, there is an urgent need to train primary health care providers should be trained – particularly in SRH and HIV-related settings – on female condom introduction and promotion. Correct female condom use is not necessarily intuitive, however, ample evidence demonstrates that efforts to increase women's comfort with, and access to the product pays off in terms of both primary and secondary HIV prevention.

Although 2011 research findings on **PrEP** were generally promising, their findings with regard to women were inconclusive. The iPrex study included transgender women but not in significant enough numbers to allow for independent efficacy analysis. The Partners PrEP trial showed effectiveness among women participating as part of a sero-discordant, heterosexual couple (a dynamic that may differ significantly from a single woman's use of the drug). The CDC's TDF 2 trial showed effectiveness among participants overall but was not large enough to show conclusively whether the levels of protection it provided to women differed from the level provided to men. The Fem-PrEP trial showed no evident protection among women enrolled. Nor did the tenofovir-only oral PrEP taken by women in the VOICE trial. We also note that the women's sub-group of the CDC Working Group to develop PrEP guidance has identified multiple barriers to PrEP acceptability and adherence among women at high risk of HIV in the US.

For all of these reasons, there is an urgent need for U.S.-based trials to assess PrEP's safety and efficacy among women, especially within the context of pregnancy and breast-feeding, and among transgender women. More evidence is needed to fully understand the impact of structural factors likely to affect women's access and adherence, as well as socio-behavioral factors (such as condom use by male partners of women using PrEP) and medical risks including the potential for women taking PrEP to develop HIV that is drug resistant if their adherence to the PrEP regimen is low.

We similarly urge the implementation of tightly focused observational studies to investigate the effectiveness and impact of **"treatment as prevention"** services specifically on women, including transgender women, served by TLC+ initiatives and accelerated comprehensive HIV/AIDS planning and cross-agency response projects such as the HHS 12 Cities Project and CDC ECHPP. Data produced by such studies, disaggregated by sex and gender, is essential to assessing the barriers to reaching, linking, and retaining women in HIV care, and the impact that earlier uptake of HIV treatment is having on participating women and girls, primarily in terms of their own health and secondarily in terms of their likelihood of transmitting HIV to others.

Establishment by the Office of AIDS Research (OAR) of the National Institutes of Health (NIH) Coordinating Committee on Women and Girls has been a valuable development and we urge this committee to mobilize around the implementation of explicitly gender-sensitive research regarding the impact of these initiatives on women. These findings will be critical to formulation of well-informed decisions about PrEP and treatment as prevention for women and communities at highest risk of HIV.

Finally, we urge this Committee to take immediate steps to further explore and explain to the public the potential **impacts of hormonal contraceptive use on HIV risk** among women and girls (especially use of the injectable contraceptive depot-medroxy-progesterone acetate **or DMPA, a generic version of Depo-Provera)**. Data published in the *Lancet* in 2011 suggest that using DPMA may double an HIV-negative woman's risk of acquiring HIV from a positive male partner, while also possibly rendering an HIV-positive woman twice as likely to transmit HIV to her partner during sex.[31] Although this observational study's data were collected in African countries, its findings raise serious concerns among many American women at high risk of HIV or those living with HIV.

The WHO conducted a technical review of the existing scientific literature on this topic and found conflicting data on the interaction of hormonal contraception use and HIV risk[32]. The need for immediate guidance for American women is understandable when one considers patterns of Depo-Provera use in the U.S. A 2002 survey showed Depo use among only 5% of American women practicing contraception; however, in the youngest of this cohort (15-24), up to 20% were Depo users.[33] More recent CDC statistics (2006-2008) also show Depo use as most prevalent among women of color in the U.S. Thirty percent of African American women and 26% of Latina women reported lifetime experience with Depo use, compared to 19% of white women[34].

Thus, there is good reason to theorize that younger women of color may likely be the primary users of Depo in the U.S., the same female sector in which HIV rates are highest. This correlation warrants the issuance of federal information and guidance regarding the impact that Depo and other hormonal contraceptives may have on HIV risk and transmission.

Conclusion

The 30 for 30 Campaign was founded to guarantee that the unique needs of women living with and affected by HIV are met in this changing health care delivery and prevention environment. The Campaign is made up of a diverse and far-reaching group of organizations from every region of the United States. We include national and local advocacy and service delivery organizations – all dedicated to ensuring that the health and rights of women living with and affected by HIV/AIDS are upheld. With confidence and urgency the Campaign encourages policy makers to take swift action to implement the HIV prevention programs and services we know work for women.

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Consultant: Anna Forbes, MSS

Member Organizations: The Afiya Center HIV Prevention & Sexual Reproductive Justice, African Services Committee, AIDS Alabama, AIDS Alliance for Children Youth & Families, AIDS Foundation of Chicago, AIDS United, Bailey House, Campaign to End AIDS (C2EA), Center for Health and Gender Equity (CHANGE), Center for HIV Law and Policy (CHLP), Community Healthcare Network, HIV Law Project, HIV Prevention Justice Alliance, Housing Works, International Community of Women Living with HIV/AIDS (ICW), IRIS Center, Memphis Center for Reproductive Health, National AIDS Housing Coalition (NAHC), National Black Leadership Commission on AIDS, Inc. (NBLCA), National Black Women's HIV/AIDS Network (NBWHAN), National Health Law Program (NHeLP), National Women and AIDS Collective (NWAC), Sisterlove. Inc., SMART University, South Carolina HIV/AIDS Council, Southern HIV/AIDS Strategy Initiative (SASI), U.S. Positive Women's Network (PWN), The Well Project, The Women's Collective, Women Organized to Respond to Life-threatening Diseases (WORLD), Women with a Vision

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